





Qualitative research among most at risk populations for TB in Health Outreach Project pilot sites in Kyrgyzstan

PROGRAM TITLE: USAID Health Outreach Program

COOPERATIVE AGREEMENT NUMBER: 176-A-00-09-00023-00

PROGRAM SITES COVERED BY REPORT: Kyrgyzstan (Pilot sites in Chui Oblast,

Osh Oblast and Jalalabat Oblast)

QUALITATIVE RESEARCH PERIOD: January-February 2010

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DATE: August, 2010

Special gratitude to:

- Employees of the local NGOs Rans Plus (Bishkek), Antistigma (Tokmok), National Society of Red Crescent, Hadysy (Bishkek), Aman Plus (Bishkek), Parents Against Drugs (Osh), Nash vzglyad (Kara-Suu), Master Radosti (Osh), Tais Plus (Bishkek), Pravo na jizn (Sokuluk), Health for all (Bishkek), Gender-Vector (Kara-Balta), Podruga (Osh), Plus Centre (Osh) for their assistance in conducting FGDs and interviews.
- The representatives of the target groups who participated in the survey for the allotted time and patience.
- Patients of TB hospitals and AIDS Centers for their contribution and participation.

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Abbreviations and Definitions

DOT Direct Observation of Treatment

DOTS WHO strategy to fight TB FGD Focus Group Discussion(s)

GFATM Global Fund to Fight AIDS, Tuberculosis and Malaria

HIV Human Immunodeficiency Virus

IDI In-depth interview IDU Injecting drug user

KAP Knowledge, Attitudes and Practice

MARP Most at risk population
MSM Men who have sex with men

PHC Primary Health Care
PLHIV People living with HIV

SW Sex worker TB Tuberculosis

TB case Person with TB disease

TB infection presence of Mycobacterium tuberculosis bacilli in the body, not necessarily

disease

1. Executive Summary

Starting in October 2009, Project HOPE, as part of the Health Outreach Program Consortium, began implementation of the "Health Outreach Program" in the areas of Chui Oblast, Osh and Jalalabad oblasts in Kyrgyzstan.

The present study used Focus Group Discussions (FGD) and in-depth interviews (IDI) to investigate the determinants of barriers and motivators for seeking care and getting treatment for tuberculosis (TB). From January to February 2010, ten in-depth interviews were conducted with people living with HIV/AIDS (PLHIV) who currently have or recently had TB disease. Over the same period, 15 FGDs with 162 persons were conducted among representatives from most at risk populations (MARP) for TB, including 44 intravenous drug users (IDU), 28 sex workers (SW), 18 men who have sex with men (MSM), 29 people living with HIV/AIDS (PLHIV), and 43 migrants from the project pilot sites. This research was focused on obtaining information about the group's knowledge, attitudes and practices on TB and to determine both barriers and motivators for seeking care and getting TB treatment.

2. Background

In Kyrgyzstan, the first activities focused on TB/HIV were started in 2004 as a part of the CAPACITY project. The project did not cover the field level; it was mostly dedicated to training and building political commitment at the national level. The first activities aimed to field issues for TB/HIV mentioned in the Global Fund 7th round program (HIV component) and in several projects supported by CAAP¹, CARHAP² and AFEW.

In 2004, Project HOPE initiated a thematic working group on TB/HIV issues, and due to this interdepartmental working group, two editions of TB/HIV MoH executive orders (prikazes) were published. The most recent joint³ order "Improving measures on fighting against HIV/Tuberculosis co-infection in Kyrgyz Republic" was published in April 2010.

The new "Health Outreach Program", funded by USAID and implemented by the Health Outreach Program Consortium (PSI, Project HOPE, AFEW, and the Kazakh Association of PLHIV) started in 2009. In the region with one of the fastest growing HIV/AIDS epidemics in the world, the Health Outreach Program Consortium targets MARPs most likely to contract or transmit HIV and TB: IDUs, SWs, migrants, MSM, prisoners, and PLHIV. Risk for TB infection is higher among IDUs, prisoners and migrants, but is particularly dangerous for PLHIV. Thus, TB interventions will specifically target these four groups, but

² Central Asia Regional HIV/AIDs Program

¹ Central Asia AIDS Control Project

³ The order was published by Ministry of Health and The State Department of Penitentiary System under the Government of Kyrgyz Republic

will also include general TB/HIV co-infection prevention messages in outreach to MSM and SW.

Formative research was designed to be conducted among MARPs to obtain information about each group's knowledge, attitudes and practices on TB and to determine barriers and determinants for seeking care and getting TB treatment. The results of the formative research will be used for revision of the National Communication Strategy on TB, revision and development of an education program for TB outreach among MARPs and development of information, education and communication (IEC) materials.

3. Objectives of this study

The objectives of this study were to:

- 1. Document the current level of knowledge about TB among MARP in pilot sites
- 2. Identify factors impeding or contributing to seeking care and getting TB treatment
- 3. Identify the above-mentioned factors covering different population subgroups, including both genders, as well as rural and urban populations.

4. Methods

A mixed methodology was followed to conduct this study among MARPs communities in Bishkek city, Chui Oblast, Osh City, Osh Oblast and Jalalabat City of Kyrgyzstan, which are Health Outreach Program pilot sites. Qualitative FGDs and in-depth interviews were conducted to determine factors impeding or contributing to seeking care and getting TB treatment.

4.1. Research Area and Participants of Focus Group Discussions

The qualitative research discussed in this report was conducted in the project pilot sites from January to February 2010. A total of 15 FGDs were conducted among key populations (MARPs) and ten in-depth interviews among PLHIV who are currently being treated or have been treated for TB, to investigate the determinants of adherence to diagnostic procedure and treatment for TB.

Table 1. FGD participants summary by population (MARPs) category & pilot site location

| Site | SW | MSM | IDU | PLHIV | Migrants | Total # of participants |
|-------------------------|----|-----|-----|-------|----------|-------------------------|
| Bishkek | 10 | | 22 | | 33 | 65 |
| Sokuluk, Chui Oblast | 8 | | 7 | 4 | | 19 |
| Kara-Balta, Chui Oblast | | 18 | | | | 18 |
| Kant, Chui Oblast | | | | 10 | | 10 |
| Osh | 10 | | 5 | 15 | 10 | 40 |

| Kara-Suu, Osh Oblast | | | 10 | | | 10 |
|----------------------|----|----|----|----|----|-----|
| Total: | 28 | 18 | 44 | 29 | 43 | 162 |

Table 2. Summary of FGD participants by NGO, key population (MARPs) category and

gender (where information is available).

| # | NGO | City/ town | Area | Key population | Number of participants | Male | Female |
|----|------------------|-------------------------|-----------|-------------------|------------------------|------|--------|
| 1 | T DI | D'.1.1 .1 | T T . 1 | | | 0 | 10 |
| 1 | Tais Plus | Bishkek | Urban | Sex workers | 10 | 0 | 10 |
| 2 | Podruga | Osh | Urban | Sex workers | 10 | 0 | 10 |
| 3 | Pravo na jizn | Sokuluk, Chui Oblast | Rural | Sex workers | 8 | 0 | 8 |
| | | | | | | | |
| 4 | Gender-vector | Kara-Balta | Semirural | MSM | 18 | 18 | 0 |
| | | | | | | | |
| 5 | Health for all | Bishkek | Urban | Migrants | 10 | 8 | 2 |
| 6 | Master Radosti | Osh | Urban | Migrants | 10 | n/a | n/a |
| 7 | Hadysy | Bishkek | Urban | Migrants | 10 | 0 | 10 |
| 8 | National Society | Bishkek | Urban | Migrants | 10 | n/a | n/a |
| | of Red Crescent | | | | | | |
| | | | | | | | |
| 9 | Pravo na jizn | Sokuluk, Chui | Rural | IDU (7) and | 11 | n/a | n/a |
| | | Oblast | | PLHIV (4) | | | |
| 10 | Parents against | Osh city | Urban | IDU (5) and | 10 | n/a | n/a |
| | drugs | | | PLHIV (5) | | | |
| 11 | Antistigma | Chui oblast | Rural | PLHIV | 10 | n/a | n/a |
| 12 | Plus Centre | Osh city | Urban | PLHIV | 10 | n/a | n/a |
| | | | | | | | |
| 13 | Nash vzglyad | Kara-Suu | Semirural | IDU | 10 | n/a | n/a |
| 14 | Aman Plus | Bishkek | Urban | IDU | 10 | n/a | n/a |
| 15 | Rans Plus | Bishkek | Urban | IDU (12) | 15 | 7 | 5 |
| | | | | and | | | |
| | | | | Migrants (3) | | | |
| | Total | | | | 162 | 33 | 45 |

^{*}n/a = data not available

FGDs with MARPs were carried out in both urban and rural areas. FGDs were to be stratified by gender if possible (not all FGDs' protocols contain information about participants' gender). They were conducted in private rooms of drop-in centers, NGO offices and places were people are working.

FGDs were conducted in both Russian and Kyrgyz languages, and FGD protocols were written down in Russian.

Local NGOs were engaged in the research process to encourage more accurate and truthful responses from MARP group representatives, as they may have greater trust in people who have already worked with them and/or their peers. The research team for each FGD consisted of the moderator, who was fluent in Kyrgyz and/ or Russian, and the transcriber.

The whole research team underwent a two-session training, which was facilitated by the TB Specialist and the Health Outreach Program Manager of Project HOPE. The trainings covered introductions to the research questions, methodological characteristics of FGD, reasons for the choice of this method for the questions to be investigated, as well as content and use of the discussion guidelines. On the second day of the training, the practical sessions were conducted.

4.2. Research Protocol and Inclusion Criteria for Participants of Indepth Interviews

Current and former TB patients among PLHIV were identified through the Bishkek TB Center, Chui Oblast TB Hospital, Republican, Osh and Jalalabad AIDS Centers. Interviews were conducted to identify any barriers encountered in obtaining TB diagnosis and treatment. Criteria for inclusion were PLHIV who have or had TB during the previous two years.

Ten one-hour in-depth interviews (IDI) were conducted among PLHIV TB patients who had previously received or who were currently on TB treatment. The participants included five persons from the Chui Oblast, one TB patient from Bishkek, two persons from Osh and two persons from Jalalabad. Seven out of ten PLHIV interviewed were currently on TB treatment. Key persons who provided contact with the respondents are officials from TB hospitals, a TB dispensary, AIDS Centers and AIDS Hospice.

Table 3. Summary of IDIs' participants by pilot site location, gender and duration of TB history.

| # | Site | Number of respondents | Gender | Diagnosed with TB | Comments |
|-------|---------------------|-----------------------|-----------------------------|--|---|
| 1. | Bishkek | 1 | Male | Almost five years ago | |
| 2. | Chui oblast | 5 | 3 males and 2 females | Four persons – less than 1 year, one person – 3 years ago | One respondent was mother of young 32-years old man currently is on in-patient treatment with TB |
| 3. | Osh oblast | 2 | Male | One person – 2 years ago, the another one – more than 10 years ago, considered as chronic TB patient | |
| 4. | Jalalabad Oblast | 2 | Male | One person was diagnosed initially in 1992, another one – 1 or 2 years ago. | |
| Total | 4 sites | 10 | 8 males / 2 | 6 respondents were | |

| - | | | | |
|---|--|---------|------------------------|--|
| | | females | initially diagnosed | |
| | | | with TB 1-2 years ago. | |

An in-depth interview protocol, adapted from Project HOPE migrant's study, was used in this study. All ten interviews were conducted by Project HOPE staff. In-depth interviews with TB patients were conducted in Russian; one interview was partially conducted in Uzbek. Informed consent was obtained from all participants at the beginning of each interview. The aims and objectives of the study were clearly explained, and participants were remunerated for their time. Data was written down in Russian, and subsequently translated into English. The interviews were conducted in January and February 2010.

4.3. Topics of Focus Group Discussions

Discussion guidelines for the FGD are given in the annex of this report. These discussion guidelines were used in the training as well as during the FGD. The topics and general questions covered were:

- 1. Knowledge about TB
- 2. Care-seeking behavior
- 3. Barriers for seeking care and getting TB treatment
- 4. Motivators for seeking care and getting TB treatment
- 5. TB stigma and discrimination
- 6. Needs for additional information on TB

4.4. Analysis of Focus Group Discussions

All FGD were written down in Russian. The context in which statements were made was taken into account according to whether an idea came up spontaneously out of the discussion or was an answer to a question or a statement by the moderator. However, the context was used to understand which topics were most important to participants. Differences among FGD with different groups were taken into account. These may help in identifying the different levels and needs of groups which need to be taken into account during program implementation. In the data analysis, the terms and concepts from the participants' own phraseology were used.

4.5. Analysis of In-depth interviews

In-depth interviews with PLHIV TB patients were analyzed to identify themes such as lack of money to pay for private consultation, the economic need to keep working, the lack of knowledge that TB could be cured, or fear of community stigma and being socially ostracized. In the data analysis, the terms and concepts from the participants' own phraseology was used to distill themes. Themes regarding reasons for PLHIV delaying seeking TB diagnosis treatment were identified.

5. Key findings

5.1. FGDs with key populations

5.1.1. Knowledge about TB

TB general awareness. The majority of FGD participants said that it is an infectious and communicable disease, mostly lung disease. Several participants believe TB is an inheritable disease. There is a link in some responses between TB and poor life conditions including poor nutrition, absence of job and bad housing. Participants among migrants attribute TB to concrete groups of people "TB is disease of alcoholics and prisoners". This point should be paid attention to in further planning of antidiscrimination informational intervention.

Main TB symptoms. Participants in all FGDs said that symptoms include cough that continues for a long period of time, cough with sputum, sputum with blood, night and day sweats, loss of appetite, weakness, easily fatigued, rise of temperature, chest pain, weight loss and shortness of breath. One person named jaundice among TB symptoms.

Means of TB transmission. Droplets as means of transmission (through air) is mentioned among responses in all FGDs. In addition to this answer, participants believe that TB could be transmitted by other means: through saliva, through using common plates and dishes, through kissing, through blood, through smoking common cigarette, TB could be inherited, communication with TB patient or just standing next to TB-infected person could be a reason of TB transmission.

There are some answers with links between the possibility of TB transmission and poor conditions existing in prisons – small and damp cells without ventilation.

Mentioning incorrect means of transmission in FGD participants' responses show misconception around means of TB transmission and fear of being infected by any contact with a TB patient.

Consequences of TB. The most frequent opinion about future of person with TB is death. Some participants said that people with TB disease could die because of visiting the doctor late. Medical consequences mentioned in participants answers: lung destruction; long continuation of TB disease or even being diseased for the rest of their lives; the necessity to take medicines permanently; getting extremely thin; damage of other organs by TB; sources of infection for other people. Rare opinions are about possibility to be cured. Some people talked about social consequences – loss of family and relatives, loss of capacity for work, becoming an invalid.

Negative consequences of TB disease are mostly frequently in answers of FGDs participants. Mentioning TB curability is very rare.

TB treatment period. Opinions vary from seven days up to the full life term. Respondents from the migrants' group don't know the duration of treatment. There were responses in the IDU group about treatment at home by traditional tools, honey, and dog fat. IDUs with inprison experience said treatment could continue from 9 months to 2 years and due to the length of treatment and side effects many TB patients could not complete the treatment course. Some respondents in SW and PLHIV groups consider TB to be an incurable illness. One person believes that treatment success depends on the desire to be cured and the "strength of mind".

People who have experienced TB treatment themselves or have the experience of seeing people with TB next to them have fewer misperceptions about the necessary TB treatment period of time.

5.1.2. Care-seeking behavior

Respondents who have stable contact with NGOs in the framework of HIV/AIDS prevention, treatment, care and support programs said the first place to seek care is the NGO they are used to visiting. The following places for care-seeking are other possibilities mentioned in respondents' answers: TB facility, primary health care facilities, places where sputum and X-ray investigation could be done. Some persons would first go to friends, relatives or a person with TB experience. Respondents from one migrants' group said their first contact would be with a healer then visit the doctor in the case where the healer's help is unsuccessful.

In most cases, the respondents correctly identified places to seek care.

5.1.3. Barriers for seeking care and getting TB treatment

The main perceived barriers are: being refused admission to medical facilities due to not having identification, due to a person being a source of infection, lack of money for diagnostics and treatment, shame and fear of stigma, neglecting this condition as serious, absence of suitable clothes to visit doctor.

Some respondents in MSM, Migrants' and PLHIV group didn't see any barriers to seeking care in medical facilities. Conditions to this are the desire to survive and finances.

The main barriers experienced were: avoidance behavior of medical facility personnel due to status of being a former prisoner and IDU; absence of documents confirming residence; necessity to pay additional fees to the doctors even if they have all their documents.

Special opinion: IDU respondents perceive that TB services are more accessible than other medical support, such as the help of a surgeon in case of an abscess.

Capability to seek care without assistance.

A significant portion of the respondents prefer to visit doctors with the support of NGO

social workers or friends and relatives who could recommend a good doctor. Support of NGO workers will help to avoid paying more money to the medical facility for different items.

Some respondents (SW and MSM groups) said they would visit a doctor independently if they have the money to do so.

General attitude toward care seeking and TB treatment

A positive attitude is based on the general perception of the necessity to treat a person with TB disease; an understanding of poor consequences in case of not receiving TB treatment; knowledge that treatment is necessary to avoid infecting other people.

A negative attitude is mostly based on absence of money to get treatment, negligence of medical staff in hospitals and refusing to treat due to absence of identification.

Several respondents could not articulate clearly their attitude toward care seeking and TB treatment.

5.1.4. Motivators for seeking care and getting TB treatment

Common motivators for seeking care mentioned in all FGDs: support of people close to them, for children, for themselves, a desire to live longer

SWs' group opinion: desire to be cured and good doctors.

PLHIV group opinion: financial support for diagnostics and treatment, having the meaning of life – job, family, confidence of treatment success.

IDUs' group opinion: danger to infect other people, NGO support, especially by food parcels and assistance to be hospitalized.

Special opinion in IDU group: "God knows more about life's duration. If I'm IDU there is no difference what my future is."

Opposite special opinion in IDU group: "Health is the first thing that we need." It is doubtful that this statement reflects feelings about the topic discussed; it reflects the result of an educational intervention, it is a declared trained attitude towards health.

Migrants' group opinion: to avoid infecting other people, fear of death.

People with more or less a long experience with disease (PLHIV) see the main motivators in concrete financial support to treatment and at the same time to be cured. All respondents would like to be sure they are not alone with their disease and that they have the support of those people closest to them.

5.1.5. TB stigma and discrimination

Opinions about what kind of people could get infected with TB or develop TB disease: IDUs, alcoholics, homeless people, inmates, vulnerable groups, ordinary people, everybody can get infected, HIV-positive people, labor migrants.

Links with conditions in FGD participants' answers: poor nutrition in prisons and rural areas, living in damp places (e.g., inmates), those with disorderly lifestyles, heavy smokers, people in close contact with TB patients, people not caring for their health, people with weak immunity, people in poverty.

Reasons for getting TB.

There were the following opinions: not maintaining personal hygiene, abusing alcohol and drugs, close contact with people with TB, delayed visit to the doctor, those who get infected because they are sick, weak immunity, damp or common bad living conditions, inheritable disease, irregular lifestyle, those who don't seek treatment can infect others, spending time in "shady gatherings", for example with formers prisoners, poor nutrition, heavy smoking, not caring for themselves or their health.

General perception of people with TB disease

Categories of opinions:

- (a) Descriptive position: just sick person who should be treated; they are the same people as we are; this could happen to anyone; unhappy people
- (b) Prescribing position (what TB person should do): they should watch over their health; people need to visit doctors in a timely manner (in order to be diagnosed and treated quickly); they need treatment to avoid infecting other people.
- (c) Blaming position: God gives everybody what he or she deserves; people who have TB are guilty of getting it, as it is possible to protect themselves.

Such statements "they are contagious" or "they could infect others" could be considered as blaming as well as just descriptive. It depends on discussion context. Current FGD protocols don't allow us to make a definite conclusion.

- (d) Avoiding position: I'm rather afraid of them; less communicating; just don't touch me; people are afraid to be infected and unwittingly try to avoid close contact with TB persons.
- (a) Supportive or proactive position: Feeling pity and sympathy; communicate with understanding; do not point a finger at them; "if I had more money I would help them"

The general perception about people with TB varies from blaming them in their disease to expressing pity and sympathy with them with a desire to help and support. Rational positions, such as the necessity to care about them or everybody could get infected, is heard in respondents' answers. The most negative opinions were heard in the migrants' group

(e.g., people with TB disease are guilty of their TB disease; it could be possible to protect themselves). This fact should be taken into account during planning an informational campaign aimed to decrease stigma and discrimination.

Familiarity with people with TB

The overwhelming majority in all FGD said they know people with TB in their circles.

Friendship with people with TB

The majority of respondents were ready to keep friendships with people who have TB. Some of them mentioned limitations, such the necessity to keep precautions. Another significant part of respondents would prefer to keep their distance from people with TB in order to avoid getting infected. A minor part of the respondents said they were ready to continue relations and support people with TB without any conditions.

5.1.6. Needs for additional information on TB

The main topics requested to be covered in informational materials: means of transmission, preventive measures, TB curability, TB symptoms, contact information of facilities where free of charge treatment and diagnostics are available, duration of treatment, vaccinations, rights, cost of TB treatment, how to investigate children for TB, pregnancy and TB, features of TB/HIV course of illness. Frequently requested formats are brochures and booklets in three languages: Kyrgyz, Russian and Uzbek. People from rural areas requested a radio format.

5.2 In-depth interview with people co-infected with TB/HIV

Background factors influencing information obtained in in-depth interviews: interviewers were notified in advance about the respondent's status – which persons are open to discuss their TB/HIV and others who have not disclosed their HIV status and are open only to discussing TB. Five respondents didn't hide their TB/HIV status and were ready to discuss it. Interviewers did not press the other five respondents to open up and discuss their HIV status. In general, this fact revealed to us that doctors in TB and AIDS facilities unintentionally could provoke stigma and discrimination around TB/HIV.

TB/HIV status: 5 respondents are open about their TB and HIV status, 5 respondents have not disclosed their HIV status

Treatment status: 7 respondents are currently getting TB treatment (in-patient and outpatient phases)

Awareness of TB symptoms: All respondents identified correctly the main TB symptoms.

Circumstances of getting TB: Only one respondent said that HIV is an unfavorable condition than can contribute to getting TB. Other respondents identified possible reasons and/or circumstances of getting TB, but without any link with HIV: close contact with TB persons, becoming too cold and poor conditions in prisons.

TB curability: All respondents are sure that TB is curable. Five respondents directly connect the TB curability with taking medicines in time and adherence to doctor's prescriptions. Two respondents mentioned healers' methods that could cure TB: dog's fat and eating insects. Four respondents mentioned healthy lifestyles (proper eating, not smoking and drinking) in order to cure TB as well.

First person or facility accessed to get help: Four respondents said that their mother/parents were to whom they went for advice when they became sick. Three persons with in-prison experience went for help to doctors or the head of the prison. Two respondents were diagnosed with TB during a prophylactic medical examination on the job. Only one respondent mentioned going for help to an NGO.

Facility where TB was diagnosed: In four cases, the TB disease was diagnosed in TB facilities, in three cases in PHC facilities and in three cases in the in-prison medical facility. A person who was suspected to have TB in a detention facility was under medical examination for three months. One respondent mentioned that TB diagnosis became possible due to a referral from an NGO to a TB facility.

Medical staff communication: Seven respondents talked about communication and printed materials provided by medical staff on the necessity for completing TB treatment, and they were satisfied with this information.

Reasons for finishing TB treatment: Only four respondents were able to formulate clear reasons: not spreading TB, avoiding recommencing TB, avoiding TB resistance and avoiding death, and to keep lungs functioning. Nevertheless, there is no link in respondents' answers between treatment completion and TB curability.

Reasons for regularity of TB treatment: Four respondents formulated clear reasons: to get treatment and to be cured. Other respondents didn't remember or were not able to tell more or less definite reasons.

Important finding: more than half of respondents were not able to connect TB curability with the necessity to take medicines in time and to complete treatment. In addition, the majority of the respondents said they were provided information on TB treatment in the medical facility.

Missing doses. Five respondents said they missed doses due to several reasons: tired of taking medicines, traveling, liver problem – hepatitis C, absence of TB drugs in that time and due to special conditions existed/existing in prison when TB person takes medicines in the medical department, hides them in their mouth and then gives them to guys from "obschak" (in-prison this is a community with significant power).

Disclosing TB status. All respondents who were not in prisons at the moment of TB diagnosis said that they told their TB diagnosis to their family or other close people. Two respondents who learned about their TB in prison told the other inmates without fail.

Social support: Seven respondents said they received food parcels as social support from NGOs. One respondent told that they currently are receiving food support due to the fact that he is HIV-positive as well.

Financial issues: Five persons told they needed to buy their own medicines. There is no clarity in answers for what type of medicines should be bought. Among these five respondents, one person from Jalalabat said it was necessary to pay the doctor directly "in order to get the proper treatment". Three respondents mentioned payments for X-rays and some tests. There are five respondents who mentioned as well the necessity to pay for additional meals, transport and hygienic items.

HIV influence on getting TB care: There was no information obtained on this topic. People with open HIV status just could say "I don't hide my HIV status". They were not able to discuss any points concerning TB/HIV. This might have happened because of poor communication by their contact persons' or their contact persons were chosen incorrectly. Medical staff who make contact with TB/HIV patients need training first of all in programmatic intervention on co-infection issues.

6. Key recommendations

6.1. Key recommendations from FGD results

6.1.1. Knowledge about TB

It is necessary to plan informational interventions with one of the main goals to correct misperceptions around means of TB transmission, because this is a key source of incommunity and in-family stigma and discrimination, as well as a source of fear to having any contact with people with TB. Informational interventions in the migrants' group should take into account discriminative statements about TB being a disease for a definite group of people, "TB is disease of alcoholics and prisoners".

6.1.2. Care-seeking behavior

The majority of key populations (MARPs) have stable contact with NGOs which are active in HIV programs for several years. It is reasonable to include TB issues in existing referral systems in Kyrgyzstan.

6.1.3. Barriers for seeking care and getting TB treatment

Informational interventions to overcome barriers for care-seeking behavior should take into consideration the main factors contributing to negative attitudes of people: absence of money to get treatment, negligence of medical staff in hospitals and refusing to treat due to absence of identification. It is necessary to highlight national rules of TB service provision.

In practicality, NGOs should build a relationship with the nearest TB service providers in order for the referral system related to TB issues to function effectively.

6.1.4. Motivators for seeking care and getting TB treatment

Promotion of seeking care and getting TB treatment should be based on the involvement of families and communities in such programs, because, first of all, people try to find support and advice from their families or close surroundings.

6.1.5. TB stigma and discrimination

Antidiscrimination campaign planning should be addressed first to communities of key populations and their families in order to overcome in-community and in-family stigma and discrimination, and then medical personnel could be involved in these activities. Supportive or proactive positions of people towards TB persons should be encouraged.

6.1.6. Needs for additional information on TB

The main topics that need to be covered in informational materials: means of TB transmission, preventive measures, TB curability, TB symptoms, contact information of facilities where free of charge treatment and diagnostics are available, duration of treatment, vaccinations, rights, cost of TB treatment, how to investigate children for TB, pregnancy and TB, and features of TB/HIV course of illness. Recommended formats are brochures and booklets in three languages Kyrgyz, Russian and Uzbek. People from rural areas requested a radio format.

6.2. Key recommendations from IDI results

6.2.1. Informational program component

An informational program component should be addressed to people with co-infection, their close relatives, NGOs and medical staff who come in contact with TB/HIV patients. It is reasonable to implement individual and/or group counseling on TB/HIV for co-infected persons and their relatives by peers and medical doctors on specific topics that could be not covered by peers alone. Medical staff should be trained on TB/HIV co-infection as well as other similar topics: stigma and discrimination, open and assertive communication.

6.2.2. Informational program content

Based on the IDIs results, co-infected patients are passive in terms of getting proper care and information on TB. They don't know exactly how they could be cured and have some misperceptions on TB curability. They are aware, in general, about the necessity for receiving and finishing regular TB treatment. They have no tools to use to keep to treatment adherence. Then co-infected persons are not aware about regulations existing in the country related to TB treatment and TB/HIV co-infection.

6.2.3. Partner organizations and referral system

NGOs which are active in the area of HIV prevention, care and support should be involved in implementing programs on TB/HIV co-infection. The existing referral system should

cover TB facilities with proper communication with its medical staff. Home-based care could be explored for those people who will continue out-patient TB treatment.

6.2.4. Social support program component

The social support program component should include not only provision of incentives but also covering other needs: transportation costs and hygiene items at a minimum.

7. Results

7.1. Participants of FGD

The results presented here cover the most sensitive or important topics: discrimination and informational needs

5b. General perception of TB infected people

IDU groups' opinions:

- They are contagious,
- Just sick person who should be treated
- Anybody could get this

Migrants groups' opinions:

- God gives everybody what he or she merits
- Unhappy people
- They are guilty of getting TB, it is possible to protect themselves
- Just don't touch me
- They need treatment to avoid infecting other people
- I sympathize with them
- They should watch over their health
- I would like it if they would not infect others
- If I have more money I will help them
- I wish them to be recovered. I would like number of ill persons becomes less and people visit doctors more quickly
- People are afraid to be infected and unwittingly try to avoid close contact with TB persons

MSM group opinions:

- Communicate with understanding
- Do not point your finger at them

SW groups' opinions:

- They should be treated
- They could infect others
- I'm feeling pity and sympathy with them
- They are the same people as we are

- I'm rather afraid of them
- Less communicating

5d. Friendship with TB persons

IDU/PLHIV groups' opinions:

- Friendship with people with TB is possible but it is necessary to adhere to hygiene rules.
- They are human beings as well. One cannot turn away from them, it is necessary to help them in getting treatment quickly.
- I have a friend with TB, but I'm keeping communication with him
- I have three relatives. They are sick for a long period of time. I keep communication with them; because we need to visit them and they come to visit us. This is a Muslim tradition.
- Person with TB raises circumspection. I'm afraid to getting sick with TB.
- I don't know, I didn't think about it.
- I was in hospital myself and got treatment. We were together, playing backgammon, eating together, food brought by our relatives, etc.

IDU groups' opinions:

- Yes, of course I would keep friendship with TB person. If tomorrow I fall sick and nobody comes to me? It's too painful.
- What should be done in this case? Abandon him? No. Just tell him to cover mouth by hand when coughing.

Migrants' groups' opinions:

- Don't know
- Perhaps, yes, but without close contacts
- Yes, he needs support after all.
- *No, I won't be able, I could fall sick as well, and I have a family.*
- It depends who this person is to me. If he is a close person, in this case I will continue [friendship]
- I don't know
- One must not be next to them, it is necessary to run away from them
- One must not talk next to them
- Yes, there are two forms of TB. I would be careful with those who have "open form". I would put on mask, for example.
- I couldn't keep former relations, I would be careful in order not to catch an illness, I would separate dishes.
- If it is closed form, is it necessary to be careful?
- Yes, it depends on TB form...
- Yes, it depends on TB form, but anyway there is a fear.
- If they are distant relatives with whom contacts are not daily, I would keep myself at distance.

SW groups' opinions:

- It depends on disease degree.
- I have no friendship relations with TB ill persons
- *I might keep friendship out of sympathy*
- I might keep friendship, but keeping precautions
- I'm keeping friendship
- Everybody could fall sick of TB, but we would try to keep friendship

MSM group's opinion:

• We might keep friendship; we are feeling pity for them.

6a and 6b. Needs for additional information on TB

| Group | Topics | Format | Language |
|-----------|---|---------------------------------------|------------------|
| MSM | TB symptoms | Trainings | Russian, Kyrgyz |
| | About TB treatment | • IEC | |
| PLHIV/IDU | Course of illness | • Video | Russian |
| | How to treat TB | • IEC | |
| | Where one can get TB drugs | | |
| | How I can feel pain in lungs | | |
| | How I can be registered | | |
| | Is TB a hereditary disease | | |
| | Features of TB/HIV course of illness | | |
| | How to investigate children for TB | | |
| IDU | Facilities where person could be | Booklets | Russian, Kyrgyz, |
| | investigated for TB | • Posters in public | Uzbek |
| | Facilities where free of charge | transport | |
| | treatment is available | • Radio | |
| | Concrete doctor who may treat | TV spots | |
| Migrants | How to prevent TB | Brochures | Russian, Kyrgyz, |
| | Where can I go in case of TB or | Books | Uzbek |
| | suspecting TB | Trainings | |
| | • TB treatment | • IEC | |
| | What drugs are used in TB treatment | • TV | |
| | How people get infected with TB | Radio (especially | |
| | Is it a curable disease | for rural areas) | |
| | Cost of TB treatment | Meeting like this | |
| | Methods and duration of TB treatment | one Booklets | |
| | Means of transmission | | |
| | Where I can go in case of first signs of TB | All available sources | |
| | | Information and | |
| | TB and pregnancy, are the what consequences | video for | |
| | Vaccination | preschool children | |
| | Who are more at risk to be infected with | F | |
| | TB | | |
| | Cost and free of charge treatment and | | |

| | diagnostics Rights for migrants | | |
|----|--|---|-----------------|
| SW | Facilities where one can get treatment What doctor should be visited Free of charge treatment Means of transmission TB symptoms Duration of treatment | Video Printed materials Brochures Booklets | Russian, Kyrgyz |

Annex 1.

Focus group Discussion Guide

A. Objectives of Focus Group Interview

- 1. What are the TB related knowledge, attitudes, practice and behavior among the target group?
- 2. What are the obstacles experienced by them to accessing heath services and getting TB treatment?

B. Target Group

SW, IDU, PLHIV, migrants and MSM

C. Introduction:

- Thank participants for coming.
- Explain what a focus group discussion is in general and explain the objective of this specific focus group.
- Explain that notes will be taken.
- Assure them that their names will not appear in any report. Their answers are confidential.
- Ask permission for use of the tape recorder before conducting FGDs and in-depth interviews.

D. **Discussion Questions:**

1. Knowledge about TB:

- 1. What do you know about TB?
 - a) What are the most important signs of TB?
 - b) How TB is transmitted?
 - c) Is TB curable?
 - d) How long is TB treatment?

2. Care seeking behavior:

- 2. If somebody has TB symptoms where he/she should go for help/advice?
 - a) Can he/she go to PHC facility or TB centers?

3. Barriers for seeking care and getting treatment:

- 3. I would like to find out, if you had TB what would prevent you from seek care and getting TB treatment?
 - a) If you wanted to seek care and treatment, would you be able to do so by yourself? Is anyone else connected to your seeking care and treatment?
 - b) How would you feel about going to seek care and treatment?

4. Motivators for care seeking and getting TB treatment:

- 4. If you had TB what would motivate you to seek care and get treatment?
 - a) Is seeking care and treatment important for you?
 - b) What kind of support would be helpful for you to seek treatment? Financial, family, friends, some kind of incentive?

5. Needs for additional information on TB:

- 5. Who can get TB? What kind of people?
 - a) Why do people get TB?
 - b) What do you think about TB patients?
 - c) Do you know somebody with TB?
 - d) Would you be friends with someone who has TB?

6. Needs for additional information on TB:

- 6. What additional information about TB would you like to receive?
 - a) In what language?
 - b) In what form would you like to receive this information?

E. Conclusions and Closure

- 1. Summarize the interview
- 2. The facilitator can review the questions, and read a few responses. The participants should be given an opportunity to correct something that was said, or add a comment.
- 3. Thank the participants and reassure them that their remarks are strictly confidential, that the information they have provided will be used to develop health messages for IEC materials.

Distribute booklet and a small gift to all the participants.